Missouri Statewide Health Information Exchange

Consumer Engagement Workgroup

Jefferson City, MO
December 16, 2009
8:30 – 10:30 am
Jefferson Building 10th Floor, Conf. Rm. B

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Agenda

Topic	Facilitator(s)	Time
Welcome & Introductions	Co-Chairs	8:30 – 8:45 am
Key Principles ➢ Review models, examples from other States ➢ Discuss proposed principles for Missouri	Co-Chairs & Manatt	8:45 – 9:30 am
Consumer Engagement Strategy ➢ Review stakeholder feedback ➢ Discuss proposed activities	Co-Chairs & Manatt	9:30 – 10:15 am
Next Steps	Co-Chairs & Manatt	10:15 – 10:30 am

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Welcome & Introductions

Governor Nixon's Remarks & Vision

➢ **This is a tremendous opportunity for Missouri – to improve the affordability, quality and value of health care.**

➢ **It is also an opportunity to bring new investment to Missouri – potentially close to a billion dollars – to create new jobs and to improve public health**

➢ **Six objectives**

- Electronic records can help **reduce costly and preventable medical errors** and avoid duplication of treatments and procedures.
- HIE can dramatically **improve the coordination of care and the quality of decision-making**, even among health care providers who are miles away from one another.
- This provides us with an opportunity to **give Missourians more complete, accurate and timely information** with which to make decisions about their own health care.
- This **makes health information portable**, so that whether consumers are switching providers or become sick while on vacation, their health history is available at the point of care.
- We believe that if done correctly, promoting the use of standardized electronic health records and interoperable systems with strict safeguards can **improve patient privacy**.
- Moving from paper records to electronic health records has tremendous potential for lowering administrative costs and thus **making health care more affordable**.

➢ *Thank you* **for partnering with the state in taking critical first steps in building a new framework for health information technology in Missouri**

Key Principles for Consumer Engagement

➢ **Establishing "Key Principles" will help to guide HIE planning activities and provide a framework for evaluating decisions with consumers' interests in mind.**

➢ **Consumer engagement principles in HIT/HIE initiatives generally address:**

- Transparency of policies and practices relating to HIT/HIE
- Consumer access to health IT tools and health information
- Confidentiality and informed consent in use of health information
- Data integrity and security safeguards for health information
- Oversight and enforcement of remedies for any security breaches or privacy violations

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Markle Foundation: Connecting for Health

- ➢ **Openness and transparency:** Consumers should be able to know what information has been collected about them, the purpose of its use, who can access and use it, and where it resides. They should also be informed about how they may obtain access to information collected about them and how they may control who has access to it.

- ➢ **Purpose specification:** The purposes for which personal data are collected should be specified at the time of collection, and the subsequent use should be limited to those purposes, or others that are specified on each occasion of change of purpose.

- ➢ **Collection limitation and data minimization:** Personal health information should only be collected for specified purposes and should be obtained by lawful and fair means. The collection and storage of personal health data should be limited to that information necessary to carry out the specified purpose. Where possible, consumers should have knowledge of or provide consent for collection of their personal health information.

- ➢ **Use limitation:** Personal data should not be disclosed, made available, or otherwise used for purposes other than those specified.

Markle Foundation: Connecting for Health

➢ **Individual participation and control:** Consumers should be able to control access to their personal information. They should know who is storing what information on them, and how that information is being used. They should also be able to review the way their information is being used or stored.

➢ **Data quality and integrity:** All personal data collected should be relevant to the purposes for which they are to be used and should be accurate, complete, and up-to-date.

➢ **Security safeguards and controls:** Reasonable safeguards should protect personal data against such risks as loss or unauthorized access, use, destruction, modification, or disclosure.

➢ **Accountability and oversight:** Entities in control of personal health information must be held accountable for implementing these principles.

➢ **Remedies:** Remedies must exist to address security breaches or privacy violations.

Consumer Partnership for eHealth: Consumer Principles

➢ Individuals should be able to **access their personally identifiable health information conveniently and affordably**.

➢ Individuals should **know how their personally identifiable health information may be used and who has access to it**.

➢ Individuals should have **control over whether and how their personally identifiable health information is shared**.

➢ Systems for electronic health data exchange must **protect the integrity, security, privacy and confidentiality of an individual's information**.

➢ The governance and administration of electronic health information networks should be **transparent, and publicly accountable**.

Consumer Partnership for eHealth: Consumer Principles

➢ Recognizing the potential of electronic patient data to support quality measurement, provider and institutional performance assessment, relative effectiveness and outcomes research, prescription drug monitoring, patient safety, public health, informed decisionmaking by patients and other public interest objectives, **systems should be designed to fully leverage that potential, while protecting patient privacy**.

➢ Implementation of any regional or national electronic health information network should be accompanied by a **significant consumer education program so that people understand how the network will operate, what information will and will not be available on the network, the value of the network, its privacy and security protections, how to participate in it, and the rights, benefits and remedies afforded to them**. These efforts should include outreach to those without health insurance coverage.

New York: NYeC Consumer Advisory Council

➢ **Openness and Transparency** – People must have notice of their rights, how they can exercise those rights, and for what purpose their health information will be shared and used.

➢ **Patient Access to Records –** People should be able to access their health information electronically, where available. Federal and state law grants people access to their own records, but electronic access is still not built-in to the policies and practices of many health entities. Access should be convenient and affordable, and people should be able to designate proxies for access to their information.

➢ **Confidentiality –** People should be able to limit the disclosure and use of their health information maintained in electronic health information systems, including health information exchange (HIE) networks. Meaningful consent, along with related protections, must be at the center of health information systems that store, disclose and use identifiable health information electronically. As electronic health information systems, including health information exchange (HIE) networks, are developed, people must be empowered to make informed choices regarding whether and for what purposes their health care providers and other participants in these systems may have access to, use and disclose their electronic health information.

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New York: NYeC Consumer Advisory Council

➢ **Security and Data Integrity –** Health information exchange networks must put in place policies and procedures to safeguard the security and integrity of identifiable health information.

➢ **Meaningful Enforcement and Remedies –** Consumers must be notified in the event of a breach (unauthorized access, use or disclosure) of their electronically maintained health information. There must be meaningful enforcement of patient access, confidentiality, and security policies, and effective remedies for violations of such privacy and security safeguards, in order for consumers to have trust and confidence in emerging electronic health information systems.

FOR DISCUSSION:
Missouri's Key Principles for Consumer Engagement

➢ **Transparency of policies and practices relating to HIT/HIE**

- Individuals should be given notice of their full rights, the terms under which their information is being accessed, by whom their information is being accessed and for what purposes the information is being used. Missouri's policies relating to health information exchange should be established in an open and transparent process informed by feedback from consumers.

➢ **Consumer access to health IT tools and health information**

- Individuals should have secure, convenient access to their health information in an affordable manner. Individuals should have the ability to designate a proxy who may access their information.

➢ **Confidentiality and informed consent in use of health information**

- Individuals should be made aware of and consent to the purposes for which personal data are collected and used. Individuals should also be able to limit the extent of personally identifiable information that may be shared. The purposes should be specified at the time of information collection, and the subsequent use should be limited to those purposes, or others that are specified on each occasion of change of purpose. Personal data should not be disclosed, made available, or otherwise used for purposes other than those specified.

FOR DISCUSSION:
Missouri's Key Principles for Consumer Engagement

- **Data integrity and security safeguards for health information**
  - The collection and storage of personal health data should be limited to that information necessary to carry out the specified purpose. The appropriate safeguards should be in place to preserve confidentiality and security of personal health information.

- **Oversight and enforcement of remedies for any security breaches or privacy violations**
  - Individuals should be notified in a timely manner of any breaches or violations and have access to meaningful legal and financial remedies.

- **Outreach and education efforts to proactively engage consumers**
  - Implementation of a statewide electronic health information network should include a significant consumer education initiative so that people understand both the value of the network and the rights, benefits and remedies afforded to them. These efforts should include outreach to vulnerable and hard to reach populations.

Consumer Engagement Strategy

➤ **What feedback did we receive regarding consumer engagement?**

➤ **What activities are being contemplated in other states?**

➤ **What consumer engagement activities are occurring in Missouri that could be leveraged?**

➤ **What are the key consumer engagement strategies that should be included in Missouri's strategic plan?**

Stakeholder Feedback

What we Asked
What are the best ways to engage consumers in the use of health information?

What We Heard
- Education and communication will be critical foundational steps.   - Build awareness through education and gain buy-in by maintaining a transparent and public planning process.   - Encourage patient involvement, decision-making and accountability in health status and patient self-management of chronic conditions.   - Convey and demonstrate the value proposition of health information technology ("what's in it for me?")   - Assure consumers that appropriate safeguards are in place to protect their health information.   - Survey consumers in a variety of settings on their preferences for accessing their health information.   - Offer consumers different methods for accessing health information.   - Supply web-based patient portals that are global (not specific to any organization).   - Consider compatibility of portals with smartphones (how many consumers may primarily access the Internet) and security/encryption features necessary.   - Assure that interfaces are well-designed, easy-to-learn and user-friendly.

FOR DISCUSSION:
Other State Strategies for Consumer Engagement

➢ Environmental scanning and evaluation

- Convene roundtables/focus groups
- Conduct preliminary polling of consumers to establish baseline readiness and set benchmarks
- Develop an annual report measuring progress for use in consumer advocacy efforts
- Conduct formal process and impact evaluation

➢ Capacity building

- Establish standing consumer advisory group with regular meetings to inform activities
- Appoint a dedicated consumer advocacy staff member to manage and coordinate daily activities
- Establish dedicated funding resources for stakeholder organizations to implement targeted consumer engagement strategies

➢ Consumer outreach and education
- Develop printed and electronic educational materials
  o Consumer tips
  o Inventory of Consumer Resources
  o Guidelines to Engage Consumers
  o Frequently Asked Questions (FAQs)
  o Glossary of Terms
  o Risks/Benefit Summary
  o Literacy and language guidelines
  o Patient Rights & Privacy Tips
  o Press kits
- Set-up and maintain website to serve as repository for materials
- Engage in traditional and social media campaigns
- Conduct education and outreach initiatives
  o Consumer awareness forums
  o "Consumer Health Month"
  o Health fairs
  o Speakers' bureau

➢ **What consumer engagement activities are occurring in Missouri that could be leveraged?**

Project Milestones & Timelines

Week	Key Topics & Discussions
12/1	➤ Initial kickoff meeting and education ➤ Review charter and project timeline
12/13	➤ Review stakeholder feedback received via web survey to date ➤ Discuss threshold questions ➤ Identify consensus recommendations for inclusion in draft Strategic Plan ➤ Identify outstanding questions to be addressed Key Decisions: Key principles, priorities for activities
1/11	➤ Review draft Strategic Plan language for presentation to Advisory Board ➤ Discuss outstanding questions and identify process for resolution Key Decisions: Key message points, draft budget and consumer engagement strategy implementation timeline and schedule
1/25	➤ Review Advisory Board's feedback and/or questions relative to Strategic Plan ➤ Identify consensus responses to Advisory Board's feedback and Strategic Plan revisions
2/8	➤ Continued working session to finalize Strategic Plan content; incorporate revisions based on Advisory Board's feedback ➤ Identify issues to be "tabled" and to be addressed by the Operational Plan Key Decisions: Issues to be addressed in Operational Plan
2/22	➤ Review final Strategic Plan ➤ Review Operational Plan components and requirements ➤ Identify Workgroup milestones and timeline through May

Next Steps

➤ **Provide additional feedback to kwallis@manatt.com by Monday, January 4, 2010**

➤ **Next Meeting: Tuesday, January 12th, 8:30 am – 11:30 am (Location TBD)**
  - Review draft Strategic Plan language for presentation to Advisory Board
  - Discuss outstanding questions and identify process for resolution

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Selected National/Multi-State Initiatives

- **Agency for Healthcare Research and Quality (funded research)**
  - "Consumer Engagement in Developing Electronic Health Information Systems" (healthit.ahrq.gov/portal/server.pt/gateway/PTARGS_0_888520_0_0_18/09-0081-EF.pdf)
  - "Barriers and Drivers of Health Information Technology Use for the Elderly, Chronically Ill, and Underserved" (www.ahrq.gov/downloads/pub/evidence/pdf/hitbarriers/hitbar.pdf)
- **Center for Democracy and Technology** (www.cdt.org/issue/health-privacy)
- **Consumer Partnership for e-Health** (www.nationalpartnership.org/site/PageServer?pagename=issues_health_hit)
- **eHealth Initiative** (www.ehealthinitiative.org/engaging-consumers-introduction.html)
- **Health Information Security and Privacy Collaborative (HISPC)** (healthit.hhs.gov/portal/server.pt?open=512&objID=1280&PageID=16051&mode=2&cached=true; secure4health.org)
- **Markle Foundation** (www.markle.org/markle_programs/healthcare/projects/index.php)

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Selected State Initiatives

➢ **Arizona Health-e Connection** (www.azhec.org/consumer_advisoryCouncil.jsp)

➢ **Georgia HealthInfo** (georgiahealthinfo.gov/cms/consumer_education_and_engagement)

➢ **Maine HealthInfoNet** (www.hinfonet.org/cons_charge.html)

➢ **Minnesota e-Health Initiative** (health.state.mn.us/e-health/)

➢ **New York eHealth Collaborative Consumer Advisory Council** (www.nyehealth.org/consumer-advocacy)

➢ **Washington State Health Care Authority Access My Health** (www.accessmyhealth.org/history.php)

➢ **West Virginia eHealthWV** (www.ehealthwv.org/eh/)

Additional list of resources compiled by HISPC available at:
georgiahealthinfo.gov/cms/files/pdf/Consumer_HIT_and_HIE_Materials_0.pdf

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